



NHS Central Register Governance Board

Terms of Reference

January 2015

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1. Purpose

This paper proposes a terms of reference for the NHSCR board in order to formalise its key role within the governance structure.

The board are asked to accept the terms of reference.

2. Background

- 2.1. The NHS Central Register (NHSCR), part of the National Records of Scotland (NRS) operates and maintains a register of NHS patients in Scotland. A fundamental review of its work was carried out in the latter half of 2003 under the leadership of the Scottish Government Health and Social Care Directorates (SGHD) Deputy Chief Medical Officer, on behalf of the NHS.
- 2.2. The [Review Group's report](#) in February 2004 established that the NHSCR is vital to the smooth running of the NHS in Scotland and proposed no change to its management arrangements. It made a number of detailed recommendations, including:-

'The NHSCR, with its host organisation, should establish governance arrangements that link with representation from key service users and offer strategic advice on its external relations, governance and effective policy developments.'

Current Management Structures for NHSCR

- 2.3. The NHSCR reports to, and is funded by, SGHD. Its key service users are the NHS Boards, NHS National Services Scotland (NHS NSS), Improvement Service, Local Authorities and medical researchers. As part of NRS it falls within the management and governance structure of NRS. NHSCR sits with the Data Resources business area with the Head of Data Resources being part of the NRS Senior Management Team. Ultimate responsibility for NHSCR lies with the Registrar General. The Privacy Advisory Committee (soon to be subsumed into the Public Benefits and Privacy Panel) with an independent chair and membership, provide advice on sharing data from the NHSCR. The committee advises the Medical Advisor (who works for NHS NSS) to the Registrar General on all applications to use NHSCR data for research purposes.

The Existing NHSCR Board

- 2.4. The NHSCR board currently draws its membership from main stakeholders but has no formal remit. It meets irregularly but at least annually to discuss relevant matters. Given the increasing importance of the NHSCR to a growing group of stakeholders it is acknowledged that the role of the board, representing the wide group of stakeholders should be formalised.

Proposed Function of the Board

2.5. The remit of the NHSCR Governance Board should be:-

‘To provide oversight and strategic advice on the operation, future developments and external relations of the NHSCR in support of the NHS in Scotland, Improvement Service, Local Authorities, medical researchers, and other users.’

More specifically it should:

- Oversee the operation of NHSCR ensuring it meets its requirements to deliver service to its customers.
- Oversee the operation of NHSCR ensuring it safeguards the citizen data in its care.
- Provide strategic direction to future developments for NHSCR.
- Review the operations of Privacy Advisory Committee PAC (soon to be subsumed into the Public Benefits and Privacy Panel) in relation to NHSCR.
- Review the operations of the Improvement Service in relation to NHSCR
- Consider emerging and important issues relevant to NHSCR
- Oversee Registration Authority Governance for NHSCR/NRS.

3. Administration of the working group

3.1. The working group will meet twice per year (or as required).

3.2. The secretariat for the working group will be provided by NHSCR.

3.3. The Governance Board meeting will be held at Ladywell House.

4. Roles and Responsibilities

4.1. The members of the Board and their roles are listed below.

Role	Name	Function
Chair	Tim Ellis	NRS, Registrar General for Scotland (CEO)
Group Member	Gerry Donnelly	NRS, Head of Data Resources
Group Member	Muriel Douglas	NRS, Head of NHSCR
Group Member	Irene Henry	NRS, Deputy Head of NHSCR
Group Member	Dr Janet Murray	NSS ISD, NRS Caldicott Guardian,
Group Member	Dr Abbe Brown	Chair of PAC
Group Member	David Knowles	NSS, Director of Practitioner and Counter Fraud Services
Group Member	Eddie Turnbull	SG, Head of e-Health
Group Member	Dr Eric Baijal	NSS, Director of Public Health
Group Member	Paul Dowie	Improvement Service, Director of Shared Service and Customer First